

Practical Hints for Caregivers

This information is designed for the person entrusted with the care of a Huntington's Disease (HD) patient. It attempts to help with the daily routine of the patient and to simply care with helpful and practical suggestions. Physicians, nurses, physical, speech and occupational therapists and other professionals who work with HD patients will want to be familiar with the contents of this page.

Introduction

The first step in understanding the Huntington's Disease person is to recognize that he or she must be treated not as someone with a single problem but with a whole series of them. Your awareness of the extent of a patient's difficulties will aid you in offering help. In addition, your understanding of the fact that HD is a progressive disorder and your knowledge of the course it generally follows will aid you in making the necessary adjustments within the environment.

Most of the material on this page is intended for the HD patient in the intermediate or early stages of the illness; those who are no longer employable or independent in activities of daily living but who are capable of being cared for with only a moderate amount of professional assistance.

The following provides changes in the daily routines designed to simplify such a patient's care. Many have been used successfully by patients and their families. In essence, the patient's activities should be scaled to ability. The patient's efforts will be rewarded with success and frustration will be reduced. With this motivation, he or she will be more likely to assume responsibility for personal care and to maintain dignity, self-confidence and a positive outlook.

Ascertain as much personal background on the patient as possible from the family. Individualize care accordingly. If the Hospital or care facility can not supply some of the utensils or other equipment mentioned here, the patient's family can be asked to provide for special needs. Most of the items mentioned are inexpensive and readily available.

Keep in mind that the HD patient is a frightened and frustrated individual who needs respect as much as physical care.

Eating

A well planned diet, high in protein and carbohydrates, is essential for the moderately advanced HD patient. If the underweight, a minimum of 3,000 calories a day may be required. This can be provided by serving smaller meals that are easier to digest.

Since appetite and energy are greatest in the morning, the early meal should provide the bulk of the daily nutritional needs. The hospital dietician should meet with the family to discuss the diet preferences of the HD patient.

The continuous movement of an HD patient speeds up their metabolism and depletes energy sooner. Thus many HD patients develop large appetites. If a patient is hungry between meals, offer milk, eggnog or a high protein supplement drink like Carnation Instant Breakfast to help maintain the carbon nitrogen balance and to provide necessary energy.

It is important to supplement a patient's diet with a daily multivitamin. It is recommended that HD patients receive an adequate supply of Vitamin B complex, Vitamin C and Vitamin E daily. Blending foods is an easy way to supply important nutrients. Blended foods can include such nutritious items as egg-nogs fortified with brewer's yeast, wheat germ, sesame seeds or soy flour. Patients should avoid junk foods, highly fried foods and alcoholic beverages.

Plastic dishes allow HD patients to feed themselves without fear of dropping or breaking things. Large plastic tumblers or children's training cups, with perforated spouts, are easier to grasp and use. HD patients may find it easier to grasp and use. HD patients may find it easier to grip large forks and spoons with curved or thick wooden handles or utensils with velcro strips that secure to a band around their hand.

Wrist weights can help reduce involuntary movement while eating but should only be used upon the recommendation of a physician or registered occupational therapist. If patients are prone to spills, using a large plastic apron prevents soiled clothing and reduces some of the frustration at mealtimes. If the bibs are used, be sure they are attractive and not babyish in anyway.

Swallowing

A cup of liquid should be filled only half-way rather than to the brim, so the patient can manipulate it more easily. And, if it does tip over, there is less to spill. Flexible straws are also very useful in many situations.

Most HD patients have difficulty swallowing due to a loss of regulatory control of the swallowing muscles. In some cases, medications that reduce mucus accumulation can facilitate food intake. Use of such medication, however, should be at the discretion of the physician. Patients who have difficulty swallowing should not be given dense or stringy food unless it is cooked well and cut into very small pieces. Food that is difficult to chew and swallow may be put through a blender. Each item should be blended and served individually so the patient can enjoy an appealing and varied diet. Avoid dry foods. They are difficult to swallow. Other foods to avoid include deep fried foods, nuts, peanut butter, etc. Additional moisture can be achieved by adding gravy, sauces, butter.

Pills can be crushed and mixed with applesauce if a patient has difficulty swallowing them. Sometimes medications are available in liquid form. (Check with your pharmacist or physician to be sure you are not crushing time release pills).

Clothing

Dressing can be so frustrating that some patients prefer to wear the same outfit every day rather than struggle with clothing. If the wardrobe is carefully selected and modified, however, these problems can be avoided.

Encourage patients to dress themselves as much as possible. They will slow. Anticipate this and schedule care accordingly. Allow time and be tactful. Remember, what patients see in the mirror largely influences what they think of themselves. Loose fitting garments with simple closures are easier to handle and less likely to restrict an individual with involuntary motions of the arms and legs. Today, most clothing is made of permanent press synthetic fabrics that are easy to clean and less likely to wrinkle. These fabrics are machine washable and some are stain resistant. Polyester pants with a full elastic waist will facilitate dressing and toileting.

Buttons and zippers are difficult for a patient to manipulate. Replace them with snaps or velcro self-closing tape. Belts and ties also poses a problem and should be avoided. Suspenders are a good substitute for belts. Zippers are easier to operate if the small, flat tab is replaced with a plastic ring or large tab.

Slip-on loafers with rubber soles are available in many styles and variations for both men and women. These are preferable to shoes with laces or buckles.

Dresses and blouses that fasten in front and bras that hook in the front make dressing easier for women.

For patients who find it difficult to keep their glasses on because of choreic movement, an elastic tied to each ear-piece and placed around the head may help to keep glasses secure.

Cleanliness

Assist patients to bathe themselves and practice good oral hygiene Dry shampoos can be a great aid. Grab bars and /or handrails in the bathroom and in strategic areas are recommended.

Smoking

Smoking presents a serious problem for patients with poor motor skills. Those who refuse to give it up should be encouraged to smoke in one area only and should not walk around with a lit cigarette. Smoking in bed can be hazardous and should be banned.

A wide bucket partly filled with sand should be placed where the patient likes to smoke, It is easier to drop ashes into a bucket than into a small ashtray and it cannot be tipped over.

Recreation

It is important not to let patients withdraw. Don't relegate them to the sidelines or leave them with only TV or a radio to occupy them. Encourage participation or occupational therapy program within the patients abilities.

The hospital physical therapist should visit, assess the patient's needs and then set up a regular program of exercise. Patient's should be encouraged to walk by themselves if possible or should be helped to walk, with assistance, several times a day.

Communication

Many patients develop slurred speech and may even become mute, These communication problems are related to difficulties in motor articulation and not to impairment in comprehension and language. A few patients become apathetic and mute due to depression or behavioral disturbances.

To help relieve these symptoms, it is necessary to keep the lines of communication open between the patient and the caregiver. To do this, however, both must work together to adapt to each communication change as it occurs. Each must be open with the other regarding the patient's ability to speak understandably. Here are some suggestions to facilitate better communication:

- Be POSITIVE.. Changes in normal communication patterns can be devised.
- Admit when you are having trouble understanding the patient - it leads to less frustration on both parts.
- Get to know and understand the patient's communicative vocabulary.
- Encourage the patient to use words or picture cards. These may be children's "flash cards", simple drawings, or magazine pictures pasted onto heavy art board. They should include pictures of words for food, drink (hot and cold), bathroom, television, chair (sit), bed (lie down), and cigarette. While the patient is mobile, the cards should be slipped into a large envelope so they can be carried around.
- Establish a definite YES and NO response as speech deteriorates, such as a nod of the head, a blinking of the eye or a flick of a finger.

Attitude

Accept the patient as he or she is at the moment. Keep reminding yourself that the HD individual has less control over feelings than you do, and has real cause for frustration. Encourage the patient to take one day at a time; to accept the challenge of today and not worry about tomorrow.

Be patient, understanding and as relaxed as possible. Those who make a faithful effort should realize that their labor is never wasted. Huntington's Disease patients who receive devoted attention always gain in some way; their life will have more meaning than it would have otherwise.

Relaxation

Relaxation has been found beneficial when choreic movements are present. Movements usually decrease when a person is relaxed. There are a variety of methods that can be utilized to diminish movement such as:

1. Progressive relaxation
2. Relaxation exercises that include closing the eyes and imaging a peaceful, restful scene
3. Yoga
4. Use of a hammock while resting or watching television

Movements decrease under the above conditions, stress, excitement, voluntary effort, etc. augments choreic movement. The use of modern gadgetry can reduce movement. Timers are great and can be set to turn electrical items on and off at regularly scheduled time.